Mind the gap: Patients' experiences and perceptions of goal setting in palliative care

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Background: Palliative care aims to support people to live as actively as possible until death. A rehabilitative approach which includes goal setting could be an important way of achieving this. Goal setting is well established in best practice guidelines for palliative care. However little is known about how the process of goal setting actually happens in practice, especially from patients' points of view. We aimed to investigate patients' expectations, experience and perceptions of goal setting in one hospice.

Methods: We conducted 15 semi-structured interviews with a sample of patients who had been admitted to a Scottish hospice for symptom control or respite. Interviews were digitally recorded, transcribed verbatim and then analysed using Framework Analysis.

Results: Participants understood and valued goal setting but did not always share their goals with hospice staff. These were often participants' own personal activity-based goals that they worked on in parallel, but not always in partnership with hospice professionals. Participants were able to adapt their goals as their situation deteriorated or changed.

Conclusions: Our findings revealed a gap between the goals that participants identified and worked towards compared with those that participants perceived the professionals focussed on. As a result, opportunities were missed for patients and professionals to work together to achieve goals which may help patients to live actively until they die.

Key words:

Hospice, Rehabilitation, Palliative care; Goal setting; Patient interviews

Introduction:

Palliative care aims to support people to live as actively as possible until death [1], but in reality this can be a complex and contradictory business. The challenge of working with patients in the face of deteriorating function has been highlighted as a tension for both professionals and patients [2,3,4,5,6]. Professionals endeavour to strike a balance between supporting patients to do *'the things that matter and continuing life'* [2:48] in the face of unpredictable deterioration. Patients may struggle to maintain a sense of their identity as capable, problem solving individuals, often within a world of shrinking possibilities [7].

Traditionally, rehabilitation is underpinned by a biopsychosocial model of illness; the World Health Organisation (WHO) International Classification of Functioning, Disability and Health [8]. Interventions can be directed at the levels of impairment, activity, participation or the environment and take into account personal factors. The aims of rehabilitation are to: optimise social participation; maximise well-being and minimise relative's stress and distress [9]. Rehabilitation is also a process that requires collaboration between the multidisciplinary team, the patient and their family, with a focus on establishing and working towards agreed goals [10,11]. This model fits well with a rehabilitative palliative care approach which *"aims to optimise people's function and wellbeing and to enable them to live as independently and fully as possible, with choice and autonomy, within the limitations of advancing illness."* [4:2]

Goal setting is acknowledged as a central component of the rehabilitation process and is also a fundamental part of palliative care [12, 13]. However, there is wide variation as to how goal setting is carried out, its purpose and what it actually means [14, 15]. A recent paper investigating goal setting in cancer rehabilitation highlighted that *"ideally, goals should mirror problems, motivation for changes, and quality of life perceived by the individual patient"* [16:1815].

In palliative care, goal setting is recommended as an intervention that can help people to live a meaningful life in the face of death [4, 17]. This is distinct from Advance care planning which has been defined as *"a process of formal decision making that aims to help patients establish decisions about future care that take effect when they lose capacity"* [17:347] . The process of goal setting is complex [11, 19, 20]. This is particularly the case in palliative care where professionals and patients try to strike a balance between affirming life and preparing for death [3]. Although there is agreement that goal setting is an important component of palliative care, it is poorly understood and opportunities for supporting patients to identify and work towards goals can be missed by professionals [21].

Understanding of goal setting in palliative care is growing but we know very little about how patients respond to, or how they perceive, goal setting in practice. We aimed to investigate patients' expectations, experience and perceptions of goal setting in one hospice.

Methods:

The research reported here is part of a larger study designed to investigate and develop goal setting practice in a hospice setting. Firstly a literature review of goal setting practice in palliative care was conducted [22]; secondly a comparative case study of goal setting practice by professionals in a hospice was carried out [21]. Alongside this, interviews were conducted with patients to find out their expectations, perceptions and experiences of goal setting while in the hospice (which is the focus of this paper). Findings from the first two phases of the study informed the development of a theory based goal setting intervention which is reported elsewhere [23].

This paper has been prepared in line with the Consolidated Criteria for Reporting Qualitative research reporting guidelines [24]. The research team was made up of a mix of academics with backgrounds in nursing, health and social sciences. The interviews were conducted by SB who had a background in health but was working in the hospice as a researcher. Throughout the research, the team discussed their world views and the potential these might have in relation to bias in data collection and analysis [25].

Interviews are commonly used as a method of finding out about phenomena from the perspective of the participant [26] and are endorsed as a way to find out about complex situations about which little is known [27]. We used semi structured face to face interviews so that we could clarify questions, be flexible in relation to patient's experiences and collect in-depth information by asking follow up or probing questions [28]. An interview topic guide was developed so that each patient was asked the same broad questions, eliciting thoughts and perspectives that could be compared. Initially we set out to interview a sample of ten patients on two occasions: once at the beginning of their admission and again just prior to or shortly after they had been discharged, so that comparisons between participant's expectations and what actually happened in relation to goal setting could be made. In practice, the second interview was only carried out on one occasion as the health of many deteriorated and they were no longer able to take part. It also proved very difficult to interview participants at the beginning of their admission as many were too ill to be approached when they first arrived. This had been anticipated this as a potential problem when designing the study and a contingency measure was written into the original proposal, that if people were unable to participate in second interviews, a larger number of participants would be interviewed on just one occasion. This was approved by the University and NHS ethics committees. As difficulties were experienced early on in managing to carry out second

interviews, we as a team agreed to interview fifteen patients on just one occasion. The interview topic guide was modified in order to take this into account.

Setting:

This research took place in the 24-bedded inpatient unit of a hospice which delivers specialist palliative care to people living in central Scotland. The areas covered are both rural and urban. Around 40% of patients who come into the hospice later return home, having had their symptoms managed. The research focused on this group of patients.

Interviews:

Interviews were carried out in various locations, dependant on choices made by the patients and their ability to mobilise. On average, each interview took forty minutes. Some were carried out in a private sitting room away from the main ward, others were conducted on the ward with the curtains closed around the patient's bed, and one was carried out in the patient's own home, once they had been discharged. The researcher (SB) made a note of where each interview took place so that this could be taken into account during analysis, as the location of the interview may have affected what people were prepared to talk about. In practice, people did not seem to be aware of their surroundings once the interview was underway, and patients talked about both positive and negative experiences, regardless of where the interview took place

Sampling:

Participants were purposively identified by hospice staff and invited in person to participate in the research if they were:

- adult patients (16 and over) with cancer or chronic life-limiting disease who were admitted for symptom control or respite;
- able to give informed consent;
- medically well enough to participate in interviews.

Participants were given an information sheet and given at least 24 hours to make up their minds about participating. If they were interested, the researcher met with patients to discuss their participation and what it would entail. Nineteen patients were asked by staff if they would like to take part and were given information about the study. Fifteen patients opted to participate.

Ethical considerations:

The protocol for this study was scrutinised and approved by the University and NHS research and ethics committees (REC Reference number: 08/S0501/98). All recording and field notes were anonymised through the use of codes and all names were changed to pseudonyms from the outset. Patients were assured that they and their families would not be identifiable in the final report and they all had the chance to ask questions about the research, including the types of questions that would be covered, prior to agreeing to take part.

Data handling and analysis:

Interviews were digitally recorded, transcribed verbatim and then analysed using Framework Analysis [29]. Following each interview, SB wrote detailed field notes, which included information about the environment as well as a descriptive summary of each patient. SB read through each transcript in order to become familiar with the data and then derived an initial thematic framework (Figure 1):

Insert Figure 1 here

SB initially coded all the data using the themes in Figure 1. ED, EH and SW read the coded data to ensure there was agreement on the initial coding. They also read a sample of original interviews to make sure all relevant data had been coded. All researchers then discussed the initial themes in relation to the original aims and research questions. Due to the rapidly deteriorating health of participants it was not possible to conduct participant checking of our analysis. After 15 interviews, no new information was discovered, so saturation was achieved.

Results:

Participants:

Fifteen patients took part in interviews: 11 women and four men. Of these, nine were under 65 and nine had a cancer diagnosis (Table 1). The patients who took part in interviews were representative of the typical range of patients who are admitted to the ward for symptom control, although in this case more women than men agreed to participate.

Insert Table 1 here

Findings:

During interviews, participants were asked to talk about what the term 'goal setting' meant to them and spoke of their experiences of goal setting during their stay in the hospice. They were asked reflect on their expectations of hospice admission and to what extent they had been involved in decision making. Participants also talked about specific goals they were hoping to achieve and how they had been supported by staff to work towards these.

Initial themes (Figure 1) were aligned with the original aims of the study which were to understand participant's expectations, experience and perceptions of goal setting, in the following way:-

- Coming into the hospice = Expectations
- What professionals do, what patients do and what gets in the way = Experience
- What does goal setting mean = Perceptions

As data was indexed, sub-themes developed and final coding charts were created (Table 2).

Insert Table 2 here

1. Expectations:

1a. Purpose of admission/goals of admission

All participants were clear about the goals of admission to the hospice. The majority of people said they had been admitted so that particular symptoms could be sorted out, and pain was typically the symptom that participants talked about. One participant, Anne, explained how she needed to be monitored by medical staff over a consistent time period so that staff could control her pain:

> "I was having terrible pain and it was getting worse. Even with the Macmillan nurses coming in and what she decided (Sandra was my nurse) and what Sandra decided was that I would actually be better in here where they could monitor me 24 hours a day" **(Anne)**

Three participants said that they had come into the hospice in order to have a rest and also to give their partners a rest. Dan had been in the hospice for respite before and appeared familiar with the idea that he could come into the hospice for this:

> "so I - needed a break, and my wife needed a break. So, I mean I come in here to have – absolute rest." **(Dan)**

Only three participants said that the goal of hospice admission was for help to become more independent. Gemma, for example said:

> "Obviously the aim is to go out as well as possible and doing as much as possible." **(Gemma)**

Most people's goals for admission were very general and focused on symptom management rather than goals based on participating in specific activities. One participant, Ruth did have a specific goal in mind which she wanted to work on:

> "Well, I thought I would just come in here for a week or two, I'd be up on my feet walking" **(Ruth)**

1b. Involvement in decision to come into hospice

Anne, Jenny, Liz and Diana talked about their initial feelings about coming into the hospice. They regarded the hospice as a place where people come to die, and it seemed that they had needed some convincing before they were admitted. Liz said that having a specific reason for admission had helped her to make the decision to come in:

> "Joan [Homecare nurse] said you know, explained about coming in here and of course I just said "hospice?", you know but – I got a bit nervous about it – but she explained to me why– and everything and the reason I was going in was for pain control and that they would start at the beginning and try and find a tablet that would work – so – um - her object was to get me in here to do this and that's why I'm here basically. And it's working." **(Liz)**

Others talked about the fact that they had been very ill prior to being admitted and so were unable to actively participate in the decision to come into the hospice:

> "Well I was very ill at the time….. So I couldna make a straight decision actually to tell you the truth" (Ruth)

For others it had been a decision made in collaboration with family:

> "It was between (my husband) and I….He said that this would be a good time for him…As long as it was a good time for me" (Kay)

In summary, participants were aware of the goals of hospice admission and, if they had been well enough, felt that they had been fully involved in the decision to come in. The reasons for admission predominantly focused on symptom management and problem resolution and there was little evidence that participants were aware of or working towards specific goals based around activity or participation when they were admitted.

2. Participants' experiences of goal setting:

Participants talked about two types of experiences in relation to goal setting in the hospice: organisational and personal. Three participants talked about some of the restrictions that they felt the hospice placed on them in relation to achieving goals. These related to how

professionals balanced risk and how opportunities for helping them work towards their goals were sometimes missed.

2a. Organisational experiences (balancing risk, missed opportunities):

Balancing risk

One participant (Ruth) voiced particular frustration about what she perceived as overly protective attitudes of staff which she found restrictive:

> 'Like I wasn't to sit on the edge of the bed cause they keep the sides up at night in case I fall over or out' **(Ruth)**

Jane also believed that staff were safety conscious and felt she needed to make sure staff knew where she was going if she wanted to go to the toilet on her own:

> 'they'll say if you want to go to the toilet, just buzz and someone will come with you which I don't require any more – I can go myself now. It's quite a short distance – but I always say to any of the staff that are about – particularly the ones who are at the station – you know, I'll just say I'm going to the toilet so they don't come and say 'where did Jane go!' **(Jane)**

Missed opportunities

Ruth, Jane and Liz all talked about the caring attitude of hospice staff and felt that at times this stopped them from being able to do things for themselves, which they believed might restrict their independence in the future:

> 'They constantly want to wash my back for me and I'm – no - I'm capable – I can do that myself, no that's – you know – you – I need to do this myself – I need to keep going with these things as long as possible.' (**Liz)**
>
> 'one of the nursing staff will say – 'do you want to get into your pyjamas now' – and I'll say right OK then, I'll get into my pyjamas now – 'Right I'll be with you' and I say no it's OK I can do that myself because I don't want to be completely – dependent on someone else – I want to do what I can.' **(Jane)**

2b. Personal experiences (adjustment/adaptation, making plans, what happens in practice)

All participants talked about their experiences on a personal level, which included how they adjusted to deteriorating health, made plans and what happened in practice.

Adjustment/adaptation

Patients talked about how they had to adjust to their illness and scale their plans and goals back accordingly. Liz said that she had recently discovered a new lump in one of her breasts. This had shattered one of her goals, which had been to go abroad with her husband:

> 'But this is all up in – as I say, I don't see that coming now at all um – The - you know the consultant oncologist told me about 6 months ago that I had 2 or 3 years left um of which,

> even I knew I might get about 18 months out of that of em – good you know maybe quite a good life you know, with not too much medical or nursing interference – you know what I mean. That's what I'd sort of, set myself as – then – but now that's – until we know what this lump is - and if it's a breast lump –There's, I mean there's no way I'm going through treatment – operations or anything – so everything is completely and utterly up in the air' **(Liz)**

Liz appeared to cope with this new, life threatening uncertainty by becoming even more determined to maintain her own independence around day to day activities. She said that nurses had suggested she try a catheter to help with some of her urinary symptoms:

> 'Oh yes, there's no way I'm giving up any of my independence. If I can – because I'm having a lot of urinary problems and em water works is just going to pot. Um And one of the nurses had mentioned catheter and of course, I nearly had a loopy.' **(Liz)**

Liz felt that having a catheter would be like 'giving in' and resolved to maintain her independence by managing her urinary symptoms in a different way. Whilst she had a different opinion to nursing and medical staff about a solution to her problem, she felt that her opinion had been listened to and that staff had been happy to support her with this decision, at least for the time being.

Other participants appeared to make more gradual adjustments as their conditions worsened (Table 3).

Insert Table 3 here

In the examples in Table 3, participants used their experiences of the limitations that illness placed on them as information and then adjusted and changed their plans accordingly. Peter summed up the importance of goal setting as a way for him to get feedback on progress:

> 'if you don't set goals, you don't set yourself targets, err – how are you going to know you're progressing.' **(Peter)**

None of the participants interviewed seemed to be unrealistic about what they could or could not manage at that point in time. This is in contrast to what professionals sometimes believe [21].

Making plans

Participants did not always tell professionals about their specific goals, but there was evidence that they made their own plans and set themselves personal goals which they wanted to achieve (Table 4).

Insert Table 4 here

In the examples in Table 4, participants appeared to set their own goals in order to push themselves and maintain their independence and control (Jane, Jenny and Dan). Peter and Ron seemed to be thinking about particular problems and working out ways to overcome them. These specific examples were goals based around activity and participation, rather than goals about controlling symptoms (impairment based). Participants themselves seemed to take on the responsibility of sorting out these goals and did not specifically involve the hospice staff or consider them as being part of the solution.

An exception to this pattern was Amy who talked about how one of the Allied Health Professionals (AHPs) had helped her to have a visit home (this lady had severe aphasia so the dialogue is broken up with hesitation. This is indicated in the text with the use of hyphens):

> 'My goals – I speak about goals – I since my husband died, I have not been able to go home. And in my heart I wanted to be in my own house – not to stay because I knew I couldn't manage – but I wanted to be there – so that I could be – feel close to him – and the wonderful Frances [AHP]– she get it all. She get it all sorted …….. And I have listened to my music and I have lie on my bed and feel close to my husband.' **(Amy)**

Amy talked about a very important, personal goal which she had been able to achieve, with the help of staff.

What happens in practice

Participants were asked if hospice staff had asked what their goals were. Only one (Susan) could remember being specifically asked about goals:

> 'she said [the doctor]– "do you have any goals in mind – when you get out of the hospice?" I says yeah, well, the first thing I want to do – I want to go down to see my sister who I hadn't seen because her husband's so ill.' **(Susan)**

The question that the staff member asked Susan in relation to goal setting appeared to be about what she wanted to achieve when she got home rather than what she wanted to do

while she was in the hospice. Another participant (Gemma) remembered being asked about goals, but this appeared to be in relation to advance care planning:

> 'they asked me – when I first came in, they asked me a barrage of questions – about how I felt about certain things – If this happened, what did I want to do. If that happened, what did I want to happen. Who did I want contacted and things like that.' **(Gemma)**

Even though participants did not appear to be explicitly asked about goals whilst in the hospice, there was evidence that they were supported to work towards specific goals. For example, Liz was supported to go home 'on pass' so she could attend her husband's birthday celebrations:

> 'But my husband's celebrations – and we've got meals booked and everything. But the girls have - what they're doing is – the bed is being held' **(Liz)**

The physiotherapist had also helped her to do some knitting:

> 'the physio's been wonderful – you know – she – because I wanted to do some knitting and things – Oh Right, we'll find the chair – low enough arms. Poor girls were pushing chairs! – but she got me organised and everything.' **(Liz)**

Liz did not feel that professionals had asked her about specific activity based goals on admission, but it was clear that the goals of knitting and attending her husband's birthday celebrations had been identified. Liz was not able to say exactly how this had happened, but did feel that the whole team had taken time to listen to her and that they had communicated with each other effectively:

> 'But they do pass on information well and are always aware of my situation – what's happening to me and where I am and you know, what my needs are – so that's good' **(Liz)**

3. Patient's perceptions about goal setting:

Patients were asked what goal setting meant to them, and this provided an insight into their beliefs about and understanding of goals.

3a. How goals are viewed/what they are

For four patients there seemed to be a contradiction between their initial response to the question '*Does the term 'goal setting' mean anything to you?'* and later responses, once they had had time to reflect on the concept of goal setting (Table 5).

Insert table 5 here

Other participants like Anne felt that setting goals was very important. She talked about how her goals had helped to keep her going:

> 'Yeah, it means a lot to me. Because when I when I was told I had cancer, you know and then I was told it was really serious, you know – after the chemo and everything, I did set goals for myself. I've got three grandkids and my oldest one was making his first Holy Communion. And I said, right. I'm gonna be there. I'm gonna be well for that. And I was – I was well for that. I was in a wheelchair. But I was well. And then I thought – my grandson – he was in a football team and there was a tournament day – a tournament day – and I thought Right I says, I'm gonna be there for that. So I was there for that.' **(Anne)**

Although Anne felt that setting goals was important, when asked if hospice staff should set goals with her, she did not feel that this would be very helpful:

> 'I would say no because if they did set goals in here, and didn't meet them or achieve them, I think it would be worse.' **(Anne)**

In fact, Anne kept her goals completely separated from her life in the hospice:

> **Researcher:** And what about – do you set yourself little goals in here, while you're here?
> **Anne:** No
> **Researcher:** Right – why do you think that is?
> **Anne:** Well it [pause] I don't know [pause] it's just [pause] haven't even thought about it since I was in. I haven't even thought about it. You know. You see, I'm just in here, and at the back of my mind I'm not in here to die.

Although a keen goal setter in her home life, Anne did not appear to feel that goal setting was relevant in the hospice.

3b. Beliefs about goal setting

Goals seemed to have different significance for individual participants. Frank talked about goals in relation to his survival. He had a broad goal to live for longer than professionals had predicted. Diana's goals were about planning for a future after she had died. Jenny talked about getting on with life once she got home. This included very ordinary things such as booking a driving test and being able to look after her children. Susan talked about long term goals such as going on holiday, but also said she wanted to be able to sit up for longer so she could use her computer. During her interview, Susan said she was in the hospice for pain

management. This seemed to be the main focus for staff, and she had not told them about things that she might want to do if her pain was better managed.

Although some participants initially felt that goal setting was of little relevance to them, everyone ultimately talked about goals that were important to them. There were a range of goals, and these appeared to concur with theoretical underpinnings of goal setting. Some goals were about maintaining hope (for example, Frank, who wanted to live past a particular date; Anne who set a series of targets to keep herself going). Other goals were about preparing for death whilst affirming life (for example, Diana who talked about writing her will and sorting out her affairs; Amy who wanted to go home for one last time to feel close to her husband). The majority of goals were about doing simple, everyday things such as washing, showering and dressing independently. Participants did not appear to believe that these 'ordinary' goals were relevant to what was happening to them during their hospice admission and did not tend to tell staff about them. Goals did however seem to be relevant and important to the majority of individuals.

Discussion:

Participants who took part in this study were all able to say why they had been admitted to the hospice. Clear aims for admission appeared to make coming into the hospice more acceptable to them. However, goals of admission were predominantly symptom or problem focused. Two participants talked about specific, activity based goals which they had discussed with staff, but the majority worked towards their goals independently of professionals. A more explicit discussion about activity based goals prior to coming into the hospice might make admission to the hospice more acceptable for some. Participants felt that, at times, opportunities for maximising their independence were overlooked. This appeared to be because of the caring attitude of staff who often wanted to do things *for* them rather than supporting them to do things for themselves and also because staff did not want patients to take unnecessary risks. The implicit nature of the goal setting process in the hospice [21] may have contributed to the fact that patients rarely articulated their personal goals to staff. As a result, professional goals (which were most likely to be problem and symptom focused) and participant's goals (which tended to be activity based) tended to run in parallel and in isolation from each other. Hence, opportunities for staff to support participants in achieving their goals were missed.

Participants for the most part understood and valued goal setting and were able to give examples of goals that were important to them. In contrast to professional's beliefs that

patients were often unrealistic [21], the patients in this study often set themselves small goals (which appeared to be realistic) and used information gained from their experiences of trying to achieve goals to inform what they did next. They were able to scale back their goals as they adapted to the limitations that progressive illness placed on them, but wanted to hold on to maintaining independence around everyday tasks for as long as possible. They valued being able to achieve even small, everyday goals.

There are similarities between the issues which have arisen from the patient interviews, and the previous case study and literature review [21, 22]: goal setting is important but the process is an implicit one; opportunities for setting goals can be missed; patients derive hope from setting, working towards and achieving goals; and patients adapt and scale back their goals as illness progresses.

Goal setting is established as an important part of palliative care which is recognised in policy, the literature and in practice [4,10,12,13,17]. Few structured approaches to goal setting currently exist, but there is an appetite for developing theory based, explicit approaches [4, 30]. Given that in both the case studies [21] and patient interviews, there was evidence that patient centred goals were missed, a more explicit, structured approach to goal setting may help improve the consistency and reach of goal setting in this hospice.

Key theories which might underpin a structured approach to goal setting in palliative care have previously been identified [22]; Hope Theory [31, 32] and Affirming life: Preparing for death [3]. Hope Theory [31, 32] provides an explanation of how people's goals adapt as illness progresses. Snyder suggests that patients can use feedback on their own goal performance as information and then adapt their goals by either developing alternative pathways to achieve goals or deciding to work towards new goals. The participants interviewed in this study reported that they used self-feedback on their performance as described by Snyder. Contrary to what professionals believed, participants reported being able to identify apparently realistic goals or scale back their goals if necessary. Based on findings from the case studies and patient interviews, Hope Theory merits further exploration as a theory to underpin a more structured approach to goal setting in palliative care.

Our findings also resonate with theories of how people adapt to life threatening illness, such as Bye's conceptual framework [3]. Participants reported that they were working towards several goals at the same time. These ranged from goals associated with everyday things (such as putting on pyjamas or walking to the toilet) to goals about the future (such as writing wills and discussing funeral arrangements). A goal setting framework that supports people to reflect on living whilst dying may support professionals working in palliative care to connect

more meaningfully with peoples experience and perception related to their own personal situation.

Limitations:

In this study we have been able to gain an insight into the patients' experience of goal setting in the hospice through the use of semi-structured interviews. There are several limitations which need to be considered. Firstly, we depended on hospice staff to initially approach patients to ask them if they would like to be interviewed. This method of recruitment has obvious disadvantages, as staff may have selected patients who they thought were particularly positive about their experiences. In addition to this, we interviewed the majority of patients within the context of the hospice, which may have altered what they said about their experiences. In practice, the patients we interviewed talked about both negative and positive experiences in relation to goal setting. Many of the patients interviewed were very ill. This limited the researcher's ability to probe and ask follow up questions. This may well have affected the quality of data. We may have obtained a wider range of views if we had carried out more interviews. However, within the timescales of this project, this was not possible.

Conclusion:

The findings from this study demonstrate that goal setting is an important part of palliative care but that it can be difficult to do. Our findings revealed a gap between the goals that participants identify and work towards compared with those that participants perceived the professionals focussed on. In practice, professionals focus on symptoms and problems rather than goals based around activity. Lack of an explicit method of goal setting leads to important goals being missed. It results in professionals and patients focusing primarily on illness rather than on what they want to achieve and what they can do to make life more meaningful. Developing a theory and evidence-based, structured approach to goal setting may help palliative care professionals to shift their thinking and help them work with each patient in a person centred way with a focus on supporting them to live actively until they die. Findings from this study, the literature review [22] and the comparative case studies [21] have informed the development and implementation of a theory based goal setting intervention which will be reported elsewhere.

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Figure 1 Initial themes

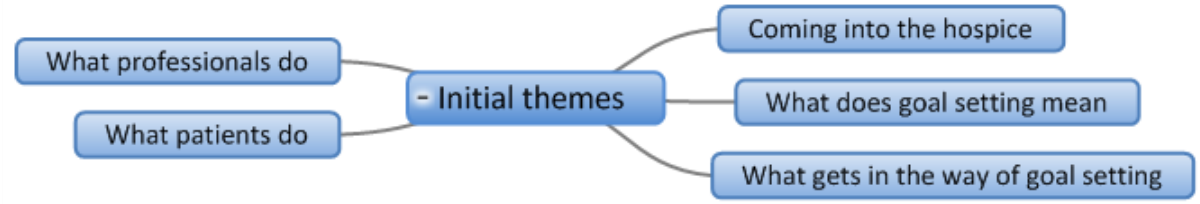

Table 1 Participants

Pseudonym	**Age**	**Diagnosis**	**Reason for admission**
Amy	Over 65	Cancer	Symptom control
Anne	Under 65	Cancer	Symptom control
Dan	Under 65	Respiratory	Symptom control
Diana	Over 65	Cancer	Symptom control
Frank	Under 65	Cancer	Symptom control
Gemma	Under 65	Respiratory	Symptom control
Gwen	Under 65	Neurological	Respite
Jane	Over 65	Cancer	Symptom control
Jenny	Under 65	Cancer	Symptom control
Kay	Under 65	Neurological	Respite
Liz	Under 65	Cancer	Symptom control
Peter	Over 65	Cancer	Symptom control
Ron	Over 65	Cancer	Symptom control
Ruth	Under 65	Cancer	Symptom control

Pseudonym	Age	Diagnosis	Reason for admission
Susan	Over 65	Neurological	Symptom control

Table 2 Final coding chart

Theme	Sub – themes
1. Expectations (Coming into the hospice)	1a. Purpose of admission/goals of admission
	1b. Involvement in decision to come into hospice
2. Experiences (What professionals do, what patients do , what gets in the way)	2a. Organisational: (Balancing risk, Missed opportunities)
	2b. Personal: (Adjustment/adaptation, Making plans, What happens in practice)
3. Perceptions (What does goal setting mean?)	3a. How goals are viewed/what they are
	3b. Beliefs about goal setting

Table 3 Examples of participants adapting to deteriorating health

Patient	Example
Gwen	**Gwen:** this is such a debilitating disease – you actually – you maybe don't know that something's no functioning till you go to – to do it – and use it – and you discover it's got weaker or it's – no functioning and that knocks the head on maybe whatever you were thinking you could manage. **Researcher**: Right – so then what? **Gwen:** Oh well, I just have to give in gracefully. But – not very gracefully – but (laughs)
Ron	So at home I sleep on a recliner. – because the toilet's downstairs. And – I'm a lot easier sleeping in that and getting out of that – but I've got hand rails on the stair – we put in for a – see if we can get a chair lift put in –but I'm maybe better without a chair lift.
Dan	To be honest, it's just with having this kind of illness, you've really got to – re-think your outlook – because as I said I thought it [a mobility scooter] was going to take away independence. It's given me more – so, I mean, the likes of MECS (Mobile Emergency Care Service) etc. is doing away with my

Patient	Example
	independence but – it won't – you know, it's just getting your head round these things.

Table 4 Plans and self-set goals

Patient	Example
Jane	'I've seen me work with young Emily [AHP student] there, and I'll say right, I'll walk to that corner and Emily will say "right, turn round if you want – if you want" and I'll say well, can I try the next corner – 'if you feel up to it and I do that, and that is my goal – is to do that wee bit more everyday.'
Jenny	'So I'd like to get hame and get things back to normal and take a wee bit of control back.'
Dan	'Well, I tend to have a shower every morning – and I manage that myself – err It takes me round about 45 minutes cause I'll go along – and I'll have a shower – then I'll sit for a little while till I get my breath back. I take this all with me (points to oxygen cylinder) – then I'll start to dry myself, then I'll have another breather – so by the time I do that, have a shave, get dressed and come back along – it can take about 45 minutes.'
Peter	'Well, we were sitting last night – or the other night and – my brother's in Melbourne with his family in Australia - and we thought that we could maybe Skype – so we brought the computer in to see how successful it might turn out to be. I cannae say it's a success yet cause we have nae got there – but err, we're certainly trying hard'
Ron	'I spoke to somebody about getting one (a zimmer) with the wheels on it. They're going to check up on that –see if they can get one delivered to the house. I use the zimmer in the house – for moving about. But, if it's a good day – well – I like a wee smoke of a wee cigar. If it's a good day, I go out – the zimmer's not much good – but the one with the wheels – would be ideal. I've got arm crutches, but I've not had them on for a wee while yet – but err. One of them would be an awful lot easier for moving about the back garden and that'

Table 5 Initial thoughts about goal setting compared with later reflections

Participant	Initial thoughts	Later reflections
Ruth	'Setting goals? Well I'm no really a goal person. I take every day as it comes'	'I've got one – goal, next year, my youngest son's getting married so I'm, that's my goal to go to his wedding so - hopefully – are you listening up there? [looks up] I want to go to his wedding so we'll wait and see what happens. It's a goal.'
Ron	**Researcher:** does the term goal setting mean anything to you? **Ron:** I've never heard of it – no.	'I want to try and get moving. [Pause]. Cause I've just been sitting in a chair.'
Gwen	**Researcher:** does the term goal setting mean anything to you? **Gwen:** Not really. No**.**	'Well, the feeding's the main one – really – I would say. And I still manage to – sort of fill in the crossword, you know. I do crosswords. Easy ones, I may say – but, em, I still manage, but sometimes I have to stop because my finger gets too – err – s – not sore because I'm no bothered with pain. It just, I run out of steam.'
Liz	**Researcher:** Do you set yourself little goals – you know – for each day? Or parts of the day? **Liz:** Um Not particularly.	'I knew I was going to get up and wash my hair today em things like that – and I want to get on with this knitting –cause – I think number two daughter might have a family quite quickly um – and I don't have the strength for – you know, knitting as I used to do – so I want to get on with that – you know – that sort of thing. So I suppose, yes I am setting myself some goals, yes.'

Mind the gap: Patients' experiences and perceptions of goal setting in palliative care

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Mind the gap: Patients' experiences and perceptions of goal setting in palliative care

Background: Palliative care aims to support people to live as actively as possible until death. A rehabilitative approach which includes goal setting could be an important way of achieving this. Goal setting is well established in best practice guidelines for palliative care. However little is known about how the process of goal setting actually happens in practice, especially from patients' points of view. We aimed to investigate patients' expectations, experience and perceptions of goal setting in one hospice.

Methods: We conducted 15 semi-structured interviews with a sample of patients who had been admitted to a Scottish hospice for symptom control or respite. Interviews were digitally recorded, transcribed verbatim and then analysed using Framework Analysis.

Results: Participants understood and valued goal setting but did not always share their goals with hospice staff. These were often participants' own personal activity-based goals that they worked on in parallel, but not always in partnership with hospice professionals. Participants were able to adapt their goals as their situation deteriorated or changed.

Conclusions: Our findings revealed a gap between the goals that participants identified and worked towards compared with those that participants perceived the professionals focussed on. As a result, opportunities were missed for patients and professionals to work together to achieve goals which may help patients to live actively until they die.

Key words:

Hospice, Rehabilitation, Palliative care; Goal setting; Patient interviews

Introduction:

Palliative care aims to support people to live as actively as possible until death [1], but in reality this can be a complex and contradictory business. The challenge of working with patients in the face of deteriorating function has been highlighted as a tension for both professionals and patients [2,3,4,5,6]. Professionals endeavour to strike a balance between supporting patients to do *'the things that matter and continuing life'* [2:48] in the face of unpredictable deterioration. Patients may struggle to maintain a sense of their identity as capable, problem solving individuals, often within a world of shrinking possibilities [7].

Traditionally, rehabilitation is underpinned by a biopsychosocial model of illness; the World Health Organisation (WHO) International Classification of Functioning, Disability and Health [8]. Interventions can be directed at the levels of impairment, activity, participation or the environment and take into account personal factors. The aims of rehabilitation are to: optimise social participation; maximise well-being and minimise relative's stress and distress [9]. Rehabilitation is also a process that requires collaboration between the multidisciplinary team, the patient and their family, with a focus on establishing and working towards agreed goals [10,11]. This model fits well with a rehabilitative palliative care approach which *"aims to optimise people's function and wellbeing and to enable them to live as independently and fully as possible, with choice and autonomy, within the limitations of advancing illness."* [4:2]

Goal setting is acknowledged as a central component of the rehabilitation process and is also a fundamental part of palliative care [12, 13]. However, there is wide variation as to how goal setting is carried out, its purpose and what it actually means [14, 15]. A recent paper investigating goal setting in cancer rehabilitation highlighted that *"ideally, goals should mirror problems, motivation for changes, and quality of life perceived by the individual patient"* [16:1815].

In palliative care, goal setting is recommended as an intervention that can help people to live a meaningful life in the face of death [4, 17]. This is distinct from Advance care planning which has been defined as *"a process of formal decision making that aims to help patients establish decisions about future care that take effect when they lose capacity"* [17:347] . The process of goal setting is complex [11, 19, 20]. This is particularly the case in palliative care where professionals and patients try to strike a balance between affirming life and preparing for death [3]. Although there is agreement that goal setting is an important component of palliative care, it is poorly understood and opportunities for supporting patients to identify and work towards goals can be missed by professionals [21].

Understanding of goal setting in palliative care is growing but we know very little about how patients respond to, or how they perceive, goal setting in practice. We aimed to investigate patients' expectations, experience and perceptions of goal setting in one hospice.

Methods:

The research reported here is part of a larger study designed to investigate and develop goal setting practice in a hospice setting. Firstly a literature review of goal setting practice in palliative care was conducted [22]; secondly a comparative case study of goal setting practice by professionals in a hospice was carried out [21]. Alongside this, interviews were conducted with patients to find out their expectations, perceptions and experiences of goal setting while in the hospice (which is the focus of this paper). Findings from the first two phases of the study informed the development of a theory based goal setting intervention which is reported elsewhere [23].

This paper has been prepared in line with the Consolidated Criteria for Reporting Qualitative research reporting guidelines [24]. The research team was made up of a mix of academics with backgrounds in nursing, health and social sciences. The interviews were conducted by SB who had a background in health but was working in the hospice as a researcher. Throughout the research, the team discussed their world views and the potential these might have in relation to bias in data collection and analysis [25].

Interviews are commonly used as a method of finding out about phenomena from the perspective of the participant [26] and are endorsed as a way to find out about complex situations about which little is known [27]. We used semi structured face to face interviews so that we could clarify questions, be flexible in relation to patient's experiences and collect in-depth information by asking follow up or probing questions [28]. An interview topic guide was developed so that each patient was asked the same broad questions, eliciting thoughts and perspectives that could be compared. Initially we set out to interview a sample of ten patients on two occasions: once at the beginning of their admission and again just prior to or shortly after they had been discharged, so that comparisons between participant's expectations and what actually happened in relation to goal setting could be made. In practice, the second interview was only carried out on one occasion as the health of many deteriorated and they were no longer able to take part. It also proved very difficult to interview participants at the beginning of their admission as many were too ill to be approached when they first arrived. This had been anticipated this as a potential problem when designing the study and a contingency measure was written into the original proposal, that if people were unable to participate in second interviews, a larger number of participants would be interviewed on just one occasion. This was approved by the University and NHS ethics committees. As difficulties were experienced early on in managing to carry out second

interviews, we as a team agreed to interview fifteen patients on just one occasion. The interview topic guide was modified in order to take this into account.

Setting:

This research took place in the 24-bedded inpatient unit of a hospice which delivers specialist palliative care to people living in central Scotland. The areas covered are both rural and urban. Around 40% of patients who come into the hospice later return home, having had their symptoms managed. The research focused on this group of patients.

Interviews:

Interviews were carried out in various locations, dependant on choices made by the patients and their ability to mobilise. On average, each interview took forty minutes. Some were carried out in a private sitting room away from the main ward, others were conducted on the ward with the curtains closed around the patient's bed, and one was carried out in the patient's own home, once they had been discharged. The researcher (SB) made a note of where each interview took place so that this could be taken into account during analysis, as the location of the interview may have affected what people were prepared to talk about. In practice, people did not seem to be aware of their surroundings once the interview was underway, and patients talked about both positive and negative experiences, regardless of where the interview took place

Sampling:

Participants were purposively identified by hospice staff and invited in person to participate in the research if they were:

- adult patients (16 and over) with cancer or chronic life-limiting disease who were admitted for symptom control or respite;
- able to give informed consent;
- medically well enough to participate in interviews.

Participants were given an information sheet and given at least 24 hours to make up their minds about participating. If they were interested, the researcher met with patients to discuss their participation and what it would entail. Nineteen patients were asked by staff if they would like to take part and were given information about the study. Fifteen patients opted to participate.

Ethical considerations:

The protocol for this study was scrutinised and approved by the University and NHS research and ethics committees (REC Reference number: 08/S0501/98). All recording and field notes were anonymised through the use of codes and all names were changed to pseudonyms from the outset. Patients were assured that they and their families would not be identifiable in the final report and they all had the chance to ask questions about the research, including the types of questions that would be covered, prior to agreeing to take part.

Data handling and analysis:

Interviews were digitally recorded, transcribed verbatim and then analysed using Framework Analysis [29]. Following each interview, SB wrote detailed field notes, which included information about the environment as well as a descriptive summary of each patient. SB read through each transcript in order to become familiar with the data and then derived an initial thematic framework (Figure 1):

Insert Figure 1 here

SB initially coded all the data using the themes in Figure 1. ED, EH and SW read the coded data to ensure there was agreement on the initial coding. They also read a sample of original interviews to make sure all relevant data had been coded. All researchers then discussed the initial themes in relation to the original aims and research questions. Due to the rapidly deteriorating health of participants it was not possible to conduct participant checking of our analysis. After 15 interviews, no new information was discovered, so saturation was achieved.

Results:

Participants:

Fifteen patients took part in interviews: 11 women and four men. Of these, nine were under 65 and nine had a cancer diagnosis (Table 1). The patients who took part in interviews were representative of the typical range of patients who are admitted to the ward for symptom control, although in this case more women than men agreed to participate.

Insert Table 1 here

Findings:

During interviews, participants were asked to talk about what the term 'goal setting' meant to them and spoke of their experiences of goal setting during their stay in the hospice. They were asked reflect on their expectations of hospice admission and to what extent they had been involved in decision making. Participants also talked about specific goals they were hoping to achieve and how they had been supported by staff to work towards these.

Initial themes (Figure 1) were aligned with the original aims of the study which were to understand participant's expectations, experience and perceptions of goal setting, in the following way:-

- Coming into the hospice = Expectations
- What professionals do, what patients do and what gets in the way = Experience
- What does goal setting mean = Perceptions

As data was indexed, sub-themes developed and final coding charts were created (Table 2).

Insert Table 2 here

1. Expectations:

1a. Purpose of admission/goals of admission

All participants were clear about the goals of admission to the hospice. The majority of people said they had been admitted so that particular symptoms could be sorted out, and pain was typically the symptom that participants talked about. One participant, Anne, explained how she needed to be monitored by medical staff over a consistent time period so that staff could control her pain:

> "I was having terrible pain and it was getting worse. Even with the Macmillan nurses coming in and what she decided (Sandra was my nurse) and what Sandra decided was that I would actually be better in here where they could monitor me 24 hours a day" **(Anne)**

Three participants said that they had come into the hospice in order to have a rest and also to give their partners a rest. Dan had been in the hospice for respite before and appeared familiar with the idea that he could come into the hospice for this:

> "so I - needed a break, and my wife needed a break. So, I mean I come in here to have – absolute rest." **(Dan)**

Only three participants said that the goal of hospice admission was for help to become more independent. Gemma, for example said:

> "Obviously the aim is to go out as well as possible and doing as much as possible." **(Gemma)**

Most people's goals for admission were very general and focused on symptom management rather than goals based on participating in specific activities. One participant, Ruth did have a specific goal in mind which she wanted to work on:

> "Well, I thought I would just come in here for a week or two, I'd be up on my feet walking" **(Ruth)**

1b. Involvement in decision to come into hospice

Anne, Jenny, Liz and Diana talked about their initial feelings about coming into the hospice. They regarded the hospice as a place where people come to die, and it seemed that they had needed some convincing before they were admitted. Liz said that having a specific reason for admission had helped her to make the decision to come in:

> "Joan [Homecare nurse] said you know, explained about coming in here and of course I just said "hospice?", you know but – I got a bit nervous about it – but she explained to me why– and everything and the reason I was going in was for pain control and that they would start at the beginning and try and find a tablet that would work – so – um - her object was to get me in here to do this and that's why I'm here basically. And it's working." **(Liz)**

Others talked about the fact that they had been very ill prior to being admitted and so were unable to actively participate in the decision to come into the hospice:

> "Well I was very ill at the time….. So I couldna make a straight decision actually to tell you the truth" (Ruth)

For others it had been a decision made in collaboration with family:

> "It was between (my husband) and I….He said that this would be a good time for him…As long as it was a good time for me" (Kay)

In summary, participants were aware of the goals of hospice admission and, if they had been well enough, felt that they had been fully involved in the decision to come in. The reasons for admission predominantly focused on symptom management and problem resolution and there was little evidence that participants were aware of or working towards specific goals based around activity or participation when they were admitted.

2. Participants' experiences of goal setting:

Participants talked about two types of experiences in relation to goal setting in the hospice: organisational and personal. Three participants talked about some of the restrictions that they felt the hospice placed on them in relation to achieving goals. These related to how

professionals balanced risk and how opportunities for helping them work towards their goals were sometimes missed.

2a. Organisational experiences (balancing risk, missed opportunities):

Balancing risk

One participant (Ruth) voiced particular frustration about what she perceived as overly protective attitudes of staff which she found restrictive:

> 'Like I wasn't to sit on the edge of the bed cause they keep the sides up at night in case I fall over or out' **(Ruth)**

Jane also believed that staff were safety conscious and felt she needed to make sure staff knew where she was going if she wanted to go to the toilet on her own:

> 'they'll say if you want to go to the toilet, just buzz and someone will come with you which I don't require any more – I can go myself now. It's quite a short distance – but I always say to any of the staff that are about – particularly the ones who are at the station – you know, I'll just say I'm going to the toilet so they don't come and say 'where did Jane go!' **(Jane)**

Missed opportunities

Ruth, Jane and Liz all talked about the caring attitude of hospice staff and felt that at times this stopped them from being able to do things for themselves, which they believed might restrict their independence in the future:

> 'They constantly want to wash my back for me and I'm – no - I'm capable – I can do that myself, no that's – you know – you – I need to do this myself – I need to keep going with these things as long as possible.' (**Liz)**
>
> 'one of the nursing staff will say – 'do you want to get into your pyjamas now' – and I'll say right OK then, I'll get into my pyjamas now – 'Right I'll be with you' and I say no it's OK I can do that myself because I don't want to be completely – dependent on someone else – I want to do what I can.' **(Jane)**

2b. Personal experiences (adjustment/adaptation, making plans, what happens in practice)

All participants talked about their experiences on a personal level, which included how they adjusted to deteriorating health, made plans and what happened in practice.

Adjustment/adaptation

Patients talked about how they had to adjust to their illness and scale their plans and goals back accordingly. Liz said that she had recently discovered a new lump in one of her breasts. This had shattered one of her goals, which had been to go abroad with her husband:

> 'But this is all up in – as I say, I don't see that coming now at all um – The - you know the consultant oncologist told me about 6 months ago that I had 2 or 3 years left um of which,

> even I knew I might get about 18 months out of that of em – good you know maybe quite a good life you know, with not too much medical or nursing interference – you know what I mean. That's what I'd sort of, set myself as – then – but now that's – until we know what this lump is - and if it's a breast lump –There's, I mean there's no way I'm going through treatment – operations or anything – so everything is completely and utterly up in the air' **(Liz)**

Liz appeared to cope with this new, life threatening uncertainty by becoming even more determined to maintain her own independence around day to day activities. She said that nurses had suggested she try a catheter to help with some of her urinary symptoms:

> 'Oh yes, there's no way I'm giving up any of my independence. If I can – because I'm having a lot of urinary problems and em water works is just going to pot. Um And one of the nurses had mentioned catheter and of course, I nearly had a loopy.' **(Liz)**

Liz felt that having a catheter would be like 'giving in' and resolved to maintain her independence by managing her urinary symptoms in a different way. Whilst she had a different opinion to nursing and medical staff about a solution to her problem, she felt that her opinion had been listened to and that staff had been happy to support her with this decision, at least for the time being.

Other participants appeared to make more gradual adjustments as their conditions worsened (Table 3).

Insert Table 3 here

In the examples in Table 3, participants used their experiences of the limitations that illness placed on them as information and then adjusted and changed their plans accordingly. Peter summed up the importance of goal setting as a way for him to get feedback on progress:

> 'if you don't set goals, you don't set yourself targets, err – how are you going to know you're progressing.' **(Peter)**

None of the participants interviewed seemed to be unrealistic about what they could or could not manage at that point in time. This is in contrast to what professionals sometimes believe [21].

Making plans

Participants did not always tell professionals about their specific goals, but there was evidence that they made their own plans and set themselves personal goals which they wanted to achieve (Table 4).

Insert Table 4 here

In the examples in Table 4, participants appeared to set their own goals in order to push themselves and maintain their independence and control (Jane, Jenny and Dan). Peter and Ron seemed to be thinking about particular problems and working out ways to overcome them. These specific examples were goals based around activity and participation, rather than goals about controlling symptoms (impairment based). Participants themselves seemed to take on the responsibility of sorting out these goals and did not specifically involve the hospice staff or consider them as being part of the solution.

An exception to this pattern was Amy who talked about how one of the Allied Health Professionals (AHPs) had helped her to have a visit home (this lady had severe aphasia so the dialogue is broken up with hesitation. This is indicated in the text with the use of hyphens):

> 'My goals – I speak about goals – I since my husband died, I have not been able to go home. And in my heart I wanted to be in my own house – not to stay because I knew I couldn't manage – but I wanted to be there – so that I could be – feel close to him – and the wonderful Frances [AHP]– she get it all. She get it all sorted …….. And I have listened to my music and I have lie on my bed and feel close to my husband.' **(Amy)**

Amy talked about a very important, personal goal which she had been able to achieve, with the help of staff.

What happens in practice

Participants were asked if hospice staff had asked what their goals were. Only one (Susan) could remember being specifically asked about goals:

> 'she said [the doctor]– "do you have any goals in mind – when you get out of the hospice?" I says yeah, well, the first thing I want to do – I want to go down to see my sister who I hadn't seen because her husband's so ill.' **(Susan)**

The question that the staff member asked Susan in relation to goal setting appeared to be about what she wanted to achieve when she got home rather than what she wanted to do

while she was in the hospice. Another participant (Gemma) remembered being asked about goals, but this appeared to be in relation to advance care planning:

> 'they asked me – when I first came in, they asked me a barrage of questions – about how I felt about certain things – If this happened, what did I want to do. If that happened, what did I want to happen. Who did I want contacted and things like that.' **(Gemma)**

Even though participants did not appear to be explicitly asked about goals whilst in the hospice, there was evidence that they were supported to work towards specific goals. For example, Liz was supported to go home 'on pass' so she could attend her husband's birthday celebrations:

> 'But my husband's celebrations – and we've got meals booked and everything. But the girls have - what they're doing is – the bed is being held' **(Liz)**

The physiotherapist had also helped her to do some knitting:

> 'the physio's been wonderful – you know – she – because I wanted to do some knitting and things – Oh Right, we'll find the chair – low enough arms. Poor girls were pushing chairs! – but she got me organised and everything.' **(Liz)**

Liz did not feel that professionals had asked her about specific activity based goals on admission, but it was clear that the goals of knitting and attending her husband's birthday celebrations had been identified. Liz was not able to say exactly how this had happened, but did feel that the whole team had taken time to listen to her and that they had communicated with each other effectively:

> 'But they do pass on information well and are always aware of my situation – what's happening to me and where I am and you know, what my needs are – so that's good' **(Liz)**

3. Patient's perceptions about goal setting:

Patients were asked what goal setting meant to them, and this provided an insight into their beliefs about and understanding of goals.

3a. How goals are viewed/what they are

For four patients there seemed to be a contradiction between their initial response to the question '*Does the term 'goal setting' mean anything to you?'* and later responses, once they had had time to reflect on the concept of goal setting (Table 5).

Insert table 5 here

Other participants like Anne felt that setting goals was very important. She talked about how her goals had helped to keep her going:

> 'Yeah, it means a lot to me. Because when I when I was told I had cancer, you know and then I was told it was really serious, you know – after the chemo and everything, I did set goals for myself. I've got three grandkids and my oldest one was making his first Holy Communion. And I said, right. I'm gonna be there. I'm gonna be well for that. And I was – I was well for that. I was in a wheelchair. But I was well. And then I thought – my grandson – he was in a football team and there was a tournament day – a tournament day – and I thought Right I says, I'm gonna be there for that. So I was there for that.' **(Anne)**

Although Anne felt that setting goals was important, when asked if hospice staff should set goals with her, she did not feel that this would be very helpful:

> 'I would say no because if they did set goals in here, and didn't meet them or achieve them, I think it would be worse.' **(Anne)**

In fact, Anne kept her goals completely separated from her life in the hospice:

> **Researcher:** And what about – do you set yourself little goals in here, while you're here?
> **Anne:** No
> **Researcher:** Right – why do you think that is?
> **Anne:** Well it [pause] I don't know [pause] it's just [pause] haven't even thought about it since I was in. I haven't even thought about it. You know. You see, I'm just in here, and at the back of my mind I'm not in here to die.

Although a keen goal setter in her home life, Anne did not appear to feel that goal setting was relevant in the hospice.

3b. Beliefs about goal setting

Goals seemed to have different significance for individual participants. Frank talked about goals in relation to his survival. He had a broad goal to live for longer than professionals had predicted. Diana's goals were about planning for a future after she had died. Jenny talked about getting on with life once she got home. This included very ordinary things such as booking a driving test and being able to look after her children. Susan talked about long term goals such as going on holiday, but also said she wanted to be able to sit up for longer so she could use her computer. During her interview, Susan said she was in the hospice for pain

management. This seemed to be the main focus for staff, and she had not told them about things that she might want to do if her pain was better managed.

Although some participants initially felt that goal setting was of little relevance to them, everyone ultimately talked about goals that were important to them. There were a range of goals, and these appeared to concur with theoretical underpinnings of goal setting. Some goals were about maintaining hope (for example, Frank, who wanted to live past a particular date; Anne who set a series of targets to keep herself going). Other goals were about preparing for death whilst affirming life (for example, Diana who talked about writing her will and sorting out her affairs; Amy who wanted to go home for one last time to feel close to her husband). The majority of goals were about doing simple, everyday things such as washing, showering and dressing independently. Participants did not appear to believe that these 'ordinary' goals were relevant to what was happening to them during their hospice admission and did not tend to tell staff about them. Goals did however seem to be relevant and important to the majority of individuals.

Discussion:

Participants who took part in this study were all able to say why they had been admitted to the hospice. Clear aims for admission appeared to make coming into the hospice more acceptable to them. However, goals of admission were predominantly symptom or problem focused. Two participants talked about specific, activity based goals which they had discussed with staff, but the majority worked towards their goals independently of professionals. A more explicit discussion about activity based goals prior to coming into the hospice might make admission to the hospice more acceptable for some. Participants felt that, at times, opportunities for maximising their independence were overlooked. This appeared to be because of the caring attitude of staff who often wanted to do things *for* them rather than supporting them to do things for themselves and also because staff did not want patients to take unnecessary risks. The implicit nature of the goal setting process in the hospice [21] may have contributed to the fact that patients rarely articulated their personal goals to staff. As a result, professional goals (which were most likely to be problem and symptom focused) and participant's goals (which tended to be activity based) tended to run in parallel and in isolation from each other. Hence, opportunities for staff to support participants in achieving their goals were missed.

Participants for the most part understood and valued goal setting and were able to give examples of goals that were important to them. In contrast to professional's beliefs that

patients were often unrealistic [21], the patients in this study often set themselves small goals (which appeared to be realistic) and used information gained from their experiences of trying to achieve goals to inform what they did next. They were able to scale back their goals as they adapted to the limitations that progressive illness placed on them, but wanted to hold on to maintaining independence around everyday tasks for as long as possible. They valued being able to achieve even small, everyday goals.

There are similarities between the issues which have arisen from the patient interviews, and the previous case study and literature review [21, 22]: goal setting is important but the process is an implicit one; opportunities for setting goals can be missed; patients derive hope from setting, working towards and achieving goals; and patients adapt and scale back their goals as illness progresses.

Goal setting is established as an important part of palliative care which is recognised in policy, the literature and in practice [4,10,12,13,17]. Few structured approaches to goal setting currently exist, but there is an appetite for developing theory based, explicit approaches [4, 30]. Given that in both the case studies [21] and patient interviews, there was evidence that patient centred goals were missed, a more explicit, structured approach to goal setting may help improve the consistency and reach of goal setting in this hospice.

Key theories which might underpin a structured approach to goal setting in palliative care have previously been identified [22]; Hope Theory [31, 32] and Affirming life: Preparing for death [3]. Hope Theory [31, 32] provides an explanation of how people's goals adapt as illness progresses. Snyder suggests that patients can use feedback on their own goal performance as information and then adapt their goals by either developing alternative pathways to achieve goals or deciding to work towards new goals. The participants interviewed in this study reported that they used self-feedback on their performance as described by Snyder. Contrary to what professionals believed, participants reported being able to identify apparently realistic goals or scale back their goals if necessary. Based on findings from the case studies and patient interviews, Hope Theory merits further exploration as a theory to underpin a more structured approach to goal setting in palliative care.

Our findings also resonate with theories of how people adapt to life threatening illness, such as Bye's conceptual framework [3]. Participants reported that they were working towards several goals at the same time. These ranged from goals associated with everyday things (such as putting on pyjamas or walking to the toilet) to goals about the future (such as writing wills and discussing funeral arrangements). A goal setting framework that supports people to reflect on living whilst dying may support professionals working in palliative care to connect

more meaningfully with peoples experience and perception related to their own personal situation.

Limitations:

In this study we have been able to gain an insight into the patients' experience of goal setting in the hospice through the use of semi-structured interviews. There are several limitations which need to be considered. Firstly, we depended on hospice staff to initially approach patients to ask them if they would like to be interviewed. This method of recruitment has obvious disadvantages, as staff may have selected patients who they thought were particularly positive about their experiences. In addition to this, we interviewed the majority of patients within the context of the hospice, which may have altered what they said about their experiences. In practice, the patients we interviewed talked about both negative and positive experiences in relation to goal setting. Many of the patients interviewed were very ill. This limited the researcher's ability to probe and ask follow up questions. This may well have affected the quality of data. We may have obtained a wider range of views if we had carried out more interviews. However, within the timescales of this project, this was not possible.

Conclusion:

The findings from this study demonstrate that goal setting is an important part of palliative care but that it can be difficult to do. Our findings revealed a gap between the goals that participants identify and work towards compared with those that participants perceived the professionals focussed on. In practice, professionals focus on symptoms and problems rather than goals based around activity. Lack of an explicit method of goal setting leads to important goals being missed. It results in professionals and patients focusing primarily on illness rather than on what they want to achieve and what they can do to make life more meaningful. Developing a theory and evidence-based, structured approach to goal setting may help palliative care professionals to shift their thinking and help them work with each patient in a person centred way with a focus on supporting them to live actively until they die. Findings from this study, the literature review [22] and the comparative case studies [21] have informed the development and implementation of a theory based goal setting intervention which will be reported elsewhere.

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Figure 1 Initial themes

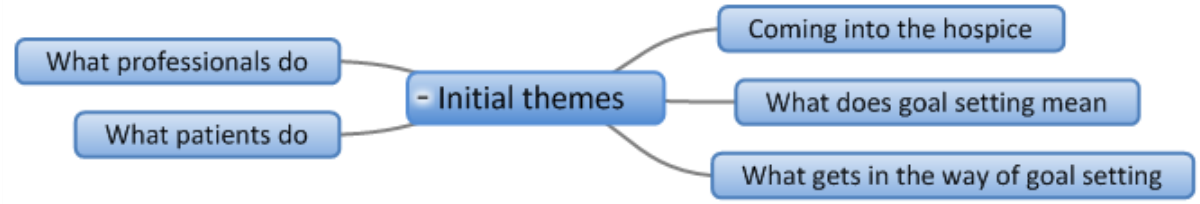

Table 1 Participants

Pseudonym	**Age**	**Diagnosis**	**Reason for admission**
Amy	Over 65	Cancer	Symptom control
Anne	Under 65	Cancer	Symptom control
Dan	Under 65	Respiratory	Symptom control
Diana	Over 65	Cancer	Symptom control
Frank	Under 65	Cancer	Symptom control
Gemma	Under 65	Respiratory	Symptom control
Gwen	Under 65	Neurological	Respite
Jane	Over 65	Cancer	Symptom control
Jenny	Under 65	Cancer	Symptom control
Kay	Under 65	Neurological	Respite
Liz	Under 65	Cancer	Symptom control
Peter	Over 65	Cancer	Symptom control
Ron	Over 65	Cancer	Symptom control
Ruth	Under 65	Cancer	Symptom control

Pseudonym	Age	Diagnosis	Reason for admission
Susan	Over 65	Neurological	Symptom control

Table 2 Final coding chart

Theme	Sub – themes
1. Expectations (Coming into the hospice)	1a. Purpose of admission/goals of admission
	1b. Involvement in decision to come into hospice
2. Experiences (What professionals do, what patients do , what gets in the way)	2a. Organisational: (Balancing risk, Missed opportunities)
	2b. Personal: (Adjustment/adaptation, Making plans, What happens in practice)
3. Perceptions (What does goal setting mean?)	3a. How goals are viewed/what they are
	3b. Beliefs about goal setting

Table 3 Examples of participants adapting to deteriorating health

Patient	Example
Gwen	**Gwen:** this is such a debilitating disease – you actually – you maybe don't know that something's no functioning till you go to – to do it – and use it – and you discover it's got weaker or it's – no functioning and that knocks the head on maybe whatever you were thinking you could manage. **Researcher**: Right – so then what? **Gwen:** Oh well, I just have to give in gracefully. But – not very gracefully – but (laughs)
Ron	So at home I sleep on a recliner. – because the toilet's downstairs. And – I'm a lot easier sleeping in that and getting out of that – but I've got hand rails on the stair – we put in for a – see if we can get a chair lift put in –but I'm maybe better without a chair lift.
Dan	To be honest, it's just with having this kind of illness, you've really got to – re-think your outlook – because as I said I thought it [a mobility scooter] was going to take away independence. It's given me more – so, I mean, the likes of MECS (Mobile Emergency Care Service) etc. is doing away with my

Patient	Example
	independence but – it won't – you know, it's just getting your head round these things.

Table 4 Plans and self-set goals

Patient	Example
Jane	'I've seen me work with young Emily [AHP student] there, and I'll say right, I'll walk to that corner and Emily will say "right, turn round if you want – if you want" and I'll say well, can I try the next corner – 'if you feel up to it and I do that, and that is my goal – is to do that wee bit more everyday.'
Jenny	'So I'd like to get hame and get things back to normal and take a wee bit of control back.'
Dan	'Well, I tend to have a shower every morning – and I manage that myself – err It takes me round about 45 minutes cause I'll go along – and I'll have a shower – then I'll sit for a little while till I get my breath back. I take this all with me (points to oxygen cylinder) – then I'll start to dry myself, then I'll have another breather – so by the time I do that, have a shave, get dressed and come back along – it can take about 45 minutes.'
Peter	'Well, we were sitting last night – or the other night and – my brother's in Melbourne with his family in Australia - and we thought that we could maybe Skype – so we brought the computer in to see how successful it might turn out to be. I cannae say it's a success yet cause we have nae got there – but err, we're certainly trying hard'
Ron	'I spoke to somebody about getting one (a zimmer) with the wheels on it. They're going to check up on that –see if they can get one delivered to the house. I use the zimmer in the house – for moving about. But, if it's a good day – well – I like a wee smoke of a wee cigar. If it's a good day, I go out – the zimmer's not much good – but the one with the wheels – would be ideal. I've got arm crutches, but I've not had them on for a wee while yet – but err. One of them would be an awful lot easier for moving about the back garden and that'

Table 5 Initial thoughts about goal setting compared with later reflections

Participant	Initial thoughts	Later reflections
Ruth	'Setting goals? Well I'm no really a goal person. I take every day as it comes'	'I've got one – goal, next year, my youngest son's getting married so I'm, that's my goal to go to his wedding so - hopefully – are you listening up there? [looks up] I want to go to his wedding so we'll wait and see what happens. It's a goal.'
Ron	**Researcher:** does the term goal setting mean anything to you? **Ron:** I've never heard of it – no.	'I want to try and get moving. [Pause]. Cause I've just been sitting in a chair.'
Gwen	**Researcher:** does the term goal setting mean anything to you? **Gwen:** Not really. No**.**	'Well, the feeding's the main one – really – I would say. And I still manage to – sort of fill in the crossword, you know. I do crosswords. Easy ones, I may say – but, em, I still manage, but sometimes I have to stop because my finger gets too – err – s – not sore because I'm no bothered with pain. It just, I run out of steam.'
Liz	**Researcher:** Do you set yourself little goals – you know – for each day? Or parts of the day? **Liz:** Um Not particularly.	'I knew I was going to get up and wash my hair today em things like that – and I want to get on with this knitting –cause – I think number two daughter might have a family quite quickly um – and I don't have the strength for – you know, knitting as I used to do – so I want to get on with that – you know – that sort of thing. So I suppose, yes I am setting myself some goals, yes.'